DOCUMENT RESUME

ED 292 246 EC 202 028

AUTHOR	Nollette, Cindy Dolby
TITLE	Autism...A Family Affair: A Curriculum for Use with Siblings of Special Needs Children.
INSTITUTION	Minneapolis Children's Medical Center, MN.
PUB DATE	85
NOTE	60p.; Second printing, April 1986.
AVAILABLE FROM	Minneapolis Children's Medical Center, ECCID, 2520 Minnehaha Ave., South, Minneapolis, MN ($11.95 + $1.50 postage and handling, discount available).
PUB TYPE	Reports - Descriptive (141) -- Guides - Non-Classroom Use (055)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	*Autism; *Behavior Disorders; *Curriculum; Early Childhood Education; Elementary Education; *Emotional Disturbances; Family Involvement; Family Life; Helping Relationship; Interaction; *Interpersonal Relationship; Intervention; Junior High Schools; Learning Activities; Program Development; Questionnaires; Self Concept; Self Esteem; *Siblings; Social Support Groups

ABSTRACT

This volume describes the Sibling Support Program at the Program for Autistic and Other Exceptional Children sponsored by Minneapolis Children's Medical Center, and includes the sibling curriculum used by the program. The curriculum was designed for children aged 4-14 who have siblings with autism or other moderate to severe disorders of interaction, communication, learning, and behavior. The program's six themes aimed to investigate individual and global issues and anxieties as well as some of the pleasures and strengths resulting from having a brother or a sister with a handicapping condition. The themes were: getting to know each other, self-identity and self-esteem, sibling relationships, understanding handicaps, family systems, and concluding discussions and activities. Seventeen sample activities are presented, each including the activity's goal, procedures, time involved, number of participants, and appropriate ages. The volume concludes with staff impressions of the sibling group's experiences and examples of pre- and post-program questionnaires and other survey forms for parents and siblings. (JDD)

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Autism . . . A Family Affair

A curriculum for use with siblings of special needs children

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Second Printing—April 1986

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EC 202028

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SECTION I

FORWARD

Autism . . . A Family Affair

The broad-range goal for this project was to develop more effective services for the families of children with moderate to severe disorders of interaction, communication, learning, and behavior. While developing this project over the 1983-84 school year, services provided for the families of autistic and autistic-type children* at Minneapolis Children's Medical Center were undoubtedly enhanced.

*Although the word "autism" is used consistently throughout this curriculum, children with a wide range of developmental disorders were served, some of whom were autistic.

ACKNOWLEDGEMENTS

Although the coordination of this project has been a cooperative effort, the ideas we gained and the energy we received were direct results of the enthusiasm, caring, pain and hope we observed in the sibling participants.

We are especially grateful for the siblings' willingness and candidness to share some aspects of their life experiences which made this project possible.

Others that we would like to thank include:

Cindy Dolby Nollette, who prepared this curriculum with assistance from the trainees and staff of Minneapolis Children's Program for Autistic and Other Exceptional Children.

The F. A. Bean Research and Education Foundation for providing us with the opportunity to sponsor the 1984 Summer Sibling project, and to fund this curriculum.

The parents of the siblings and special needs children for their ongoing support, input and assistance to the program.

The staff of the Sibling Program who collaboratively and individually worked long and hard on this project and who developed as a staff and grew as individuals.

PREFACE

"Your child has autism." These could be the first diagnostic words of a professional such as a pediatrician, educator, or mental health worker. The strong, intuitive, conflicting thoughts which parents experience when worrying that something is wrong with their youngster are instantly coupled with the frightening, remote, and chilling words of someone from whom they sought help.

They may argue. They may cry. They may deny. Some will feel relief. Some will resist. Many will look elsewhere for help. All are in real pain. Thoughts of the future loom heavily. Parents are bombarded with information that may shatter their dreams, hopes, and life expectations. There will need to be major lifestyle adjustments in the family system in order to meet the demands and needs of the child who has been labelled autistic.

Parents and other children in the family will be affected by the condition as soon as they become aware of it. The degree to which brothers and sisters of children with handicapping conditions such as autism are affected and the many issues with which they are presented are just beginning to be understood.

Little is known about the effects on family members of living with a child who has a handicapping condition. In many ways, it seems that the fields of special education and mental health treatment have begun to change in more recent years. It used to be that education and treatment were designed solely around the needs of the diagnosed individual or "identified patient." In more recent years, it has come to our awareness that persons with special needs, whether it be a handicapping condition such as autism or a chronic medical disorder such as leukemia, tend to affect all those who have contact with them. Consequently, more professionals are attempting to meet the needs of family members by offering such services as support groups, individual and family counseling and/or therapy, local and national support and information organizations, and so on. There are also existing sibling programs in the areas of mental retardation, autism, and cerebral palsy. Frequently these programs have attempted to train siblings as "co-therapists" or "behavior modifiers." Other programs have offered sibling support groups.

The theoretical foundation of the program that will be described in these pages is based partially on the small amount of work that has been done with siblings who have lost a brother or sister due to chronic illness but has primarily grown out of the responses of the siblings of children that have attended the Program for Autistic and Other Exceptional Children.

In 1981, during our special summer project, our staff began to look more closely at the needs of siblings and attempted to respond to the concerns of parents with an informally-designed summer sibling program. Since that time, a more formally organized and more structured support program has been designed based on the responses of siblings and the observations of our staff. In the summer of 1984 this

program was attended by 27 siblings who ranged in age from 3 to 15 years. The main purposes of the sibling group were:

(1) **educational**—to offer siblings a better understanding of a wide variety of handicapping conditions; to increase their understanding of labels used in special education and treatment practices; and to offer participating siblings a more formal sense of typical and atypical child development.
(2) **cathartic**—to offer siblings one form of individual and group emotional support.
(3) **social-emotional**—to offer siblings an environment in which they can meet other siblings/peers who have experienced similar life situations.
(4) **interactional**—to increase the siblings' capacity to interact in more mutually satisfying and reciprocal ways with their brother or sister who has special needs.

The curriculum in these pages attempts to summarize some of what we have learned and may be used as a guide to the development of other intervention programs for this unique population.

INTRODUCTION

The diagnosis of a handicapping condition in a family member is a painful and traumatic event for everyone in the family. It is the beginning of a long process during which family members mourn the loss of the child they had once envisioned. In many ways, a long-term handicapping condition such as autism is similar to a chronic illness in the respect that the symptoms do not go away. These symptoms are typically more stressful at some times than others. In other ways, the diagnosis of a handicapping condition is similar to a death in the family and the reaction surrounding it. The major difference about the diagnosis of this handicapping condition is that it does not have an illness's potential for recovery nor the finality of death.

Adjustment to the handicapping condition is a process that often consists of a long period of stress and reorganization within the family system. It is a process during which the family system changes and each member typically changes.

As we have worked with parents over the years, they have repeatedly expressed concern about the impact the child with the handicapping condition has on the other children in the family. Parents often wonder how the sibling is coping with the stresses of living with a handicapped brother or sister. Parents sometimes wonder how can ever meet the needs of the other children in the family when their handicapped child requires continuous supervision and attention and when parenting a handicapped child entails a seemingly endless stream of meetings with mental health, medical, and educational professionals.

It has been our experience that the siblings of handicapped children are usually an ignored population in the mental health field unless/or until they present serious enough behavioral or emotional difficulties themselves that they are brought to the attention of schools and mental health professionals.

From our perspective, siblings of children with a handicapping condition such as autism might be viewed as at high risk for potentially experiencing stress syndromes. If this is the case, it would seem to make some sense to look at the typical sequelae of the development of such stress with the goal of designing options for intervention to assist in restoring individual and family equilibrium.

After the child with the handicapping condition has been diagnosed, or the family's suspicions have been confirmed that, yes indeed, they do have a child with special needs in the family, the stage is set for the longest period of grieving and adjustment. This phase is usually long-term and more stressful at some times than others. Since the condition impacting the family is chronic, a complex combination of variables intermix over a long period of time.

Family members cope adaptively or maladaptively, and their coping style can change from time to time. For some of us in the mental health profession, one measure of the family's health is its capacity to achieve each stage, to surmount each crisis, and throughout the stressful times (which there always are) to

maintain generally positive interactions. The dysfunctional family then, is the family that is unable to find a new balance. Stressing life factors tend to instigate further family distress and crisis. Family members tend to become conflicted individuals, the family system remains imbalanced and conflicted, and the reality-based life stresses become incredibly difficult to figure out and overcome.

Within our program, each sibling reacted differently, but all siblings seemed to react to a sense of loss as well as to a distressed personal and family equilibrium. Because siblings experience a sense of loss in coming to terms with the feelings they have about their brother or sister with special needs, it is of critical importance to consider the basic phases of grieving and adjustment when working with such children.

Many siblings tend to go through stages which parallel those experienced by their parents. Environmentally the way in which parents cope offers a model for the siblings.

The three grieving phases observed generally centered around the time of diagnosis for the child with the handicapping condition: (1) The pre-diagnostic level of functioning is the time of increasing awareness that something is wrong and needs further investigation; (2) the move to confirmation of worries about the condition, hopefully leading to the diagnosis and more clarification about the condition; and (3) what happens after the diagnosis, during the long-term adjustment process.

Initially, there tends to be an increased awareness that something is wrong and needs further investigation. Parents and siblings alike begin to become suspicious that this child is not developing typically. They might wonder about unusual behavior such as peculiar hand movements, lack of relatedness to people, unusual or different play with toys, and deviances in language development. Typically a family begins to seek help for such suspicions. This is the pre-diagnostic phase and in many ways it sets the standard for living and thereby can be considered the ultimate goal of intervention; i.e. the goal of intervention is to help bring about restored functioning. The ability to adjust to chronic stress, crisis, and imbalanced family status needs to be compared to the ways in which individuals coped prior to the impact of the handicapping condition. Some issues to consider for siblings include: How did the sibling cope with role confusion and disorganization prior to the impact? What was the child's role in the transactional family unit? How did the child handle and resolve conflict? Again during treatment, all of these need to be considered and compared to the ways that siblings coped prior to the confirmation of the handicapping condition. It is extremely important to keep in mind that it is the unique combination of innate physical characteristics of every sibling paired with the parental behavioral model that together provide the foundation for coping.

Every family, and every individual within the family, tends to react quite differently to the confirmation of worries that they have been experiencing about the condition and to the long-term adjustment process. One 7-year-old sibling, after hearing about the diagnosis of her younger brother's special needs, wrote one of our staff therapists the following letter:

> Do you know what starts autism? Will I be taking the bus to summer school? Are me and Bobby going to the same school? Can you cure Bobby? Just being there that one time I see you are a great teacher. Love, Patty

Some siblings develop psychosomatic behaviors including rapid eye blinking, stomachaches, and headaches. Most siblings express some feelings of guilt, although the reason for the guilt is varied. At times the siblings verbalize a wish that they too could have problems. At other times they share concerns about what they did to cause the problems. Some actively project anger outside the family boundaries.

The diagnostic and labelling period can be emotionally upsetting and particularly eventful for all family members. The predicted developmental course of the impacting condition and how sequelae are presented to and understood by the family is important. The degree of the handicap may impose even stricter limitations on the capacity of siblings for maintaining equilibrium. It was quite typical during our experiences with siblings to have siblings describe situations they were confused about and had difficulty understanding and accepting. The situations they described were typical of the every day, reality-based occurrences in the life of families who have a handicapped child: Some siblings described feelings of frustration and/or anger because their brother or sister with special needs was unable to play with them and offer them the same kinds of mutual satisfaction that other children in the neighborhood are able to offer them. During one support group, the discussion focussed around the siblings' feelings about this situation. One 9-year-old, Johnny, stated that his autistic-like brother "does some weird things, so the other kids don't want him around." When Johnny was asked to help us better understand what that meant for him, he said, "Sean (his brother with special needs) throws a lot of tantrums. He gets mad if we don't do what he wants. Sometimes he is uncontrollable. He doesn't like to play with the same toys we do. He likes to play with ants and flies and to watch his yarn animals spin around."

Oftentimes siblings expressed feelings of confusion and wondering because their brother or sister looked so normal and so typical in so many ways, yet at the same time required countless medical and/or therapy appointments, in addition to being placed in a special education classroom in a different school from the other children in the family. Other siblings expressed confusion and worries about the stress that their parents were experiencing in addition to the conflicted anger at their parents' unavailability (physically and emotionally) to do things with them or just be with them. We frequently heard comments like, "My mom is too tired to go to my ball game," "My dad needs to work more to pay for all of Jeremy's therapy."

Some siblings clearly came to have feelings of resentment and animosity toward their brother or sister who was felt to be instigating the family crisis. Sometimes, the handicapped child in the family became the scapegoat—the person that was blamed for the many changes and upsets that had occurred within the family system.

For some siblings, the obvious appearance of the impacting condition seemed to facilitate the process of coming to terms with the stress derived from the diagnostic condition. Kathy, a 10-year-old sibling participating in the sib group for the first time, in many ways initially appeared the least anxious (of other group participants) about her 7-year-old brother having a handicapping condition. What seemed to make a difference for her was the visibility of a physical impairment (misshapen and partial paralysis) in his right arm that highly restricted the use of the arm. This child also had a severe language processing disorder in addition to severely delayed and atypical social-emotional development. When Kathy described her brother's special needs, she tended to focus on his physical limitations although from our staff's perspective they were not as severe and limiting as his other special needs.

For other siblings, the absence of the physical indicators of the condition was a hurdle to healthy coping. One 10-year-old sibling remarked, "Mark (the child with autism) looks just fine. He is not going to be in the school for the kids in wheelchairs and for the kids who are retarded." This child was able to label and describe many of his brother's special needs. However, one of the complicating factors was the fact that his brother looked okay physically. In other words, there were no obvious demarcating features of this child's handicapping condition. It was only when one spent time with this child or did more than casual observation that one was able to see the serious, yet invisible, handicap.

The Sibling Support Program at the Program for Autistic and Other Exceptional Children sponsored by Minneapolis Children's Medical Center is one option for support and intervention for the siblings. Hopefully, if each family receives early contact and support with concerned and aware social service professionals, ongoing support and networking services can be established. A support program such as which we have designed for siblings is not an easy "cure-all" to remediate or "fix" the difficulties that a family encounters. All families live with stressful and stressing situations. Human dynamics and caring interactions can also be stressing. Living with a child who has special needs can also be stressing. The primary role of our sibling program is to offer support and guidance and involve families in such a way that typical, life-stressing situations do not become distressing and devastating life experiences.

SECTION II

SAMPLE DESCRIPTION: CURRICULUM FOR SIBLING PROJECT

The following section serves as a model for others who are interested in designing support and intervention programs for a similar population of children. This model is not meant to be implemented exactly as described, but rather to serve as a take-off point for others.

The sibling program that will be described operated as a four day a week, three hour a day, six-week project. The Summer Sibling Group ran at the same time and in the same building as the special needs project. The Sibling Program was designed for children 4-14 years of age. However, a 15-year-old sibling attended and worked as an assistant for a small stipend which she received at the end of the project. Occasionally, usually on a day that a parent group ran, children younger than four years would attend. If they were able to, they participated in the scheduled, but often modified, activities or at other times the 15-year-old assistant supervised them in "sibling daycare."

For the sake of organization (and supervision!) the siblings were divided by chronological age into two groups. One group was for children ages 4-8 years, and the other group was for children 9-14 years. Sibling staff was comprised of students and professionals from a wide variety of fields including psychology, social work, art therapy, medicine, nursing, and education. Each sibling group was assigned 1-2 sibling leaders who were responsible for implementing and assisting in daily activities, supervision, and some small group and individual counseling. Volunteers came in on a daily basis and would assist the main staff. A certified art therapist worked with large and small groups of siblings, in addition to providing some individual therapy with siblings and/or design activities that the siblings could do together with their brother/sister with special needs.

In addition to the daily group activities, siblings (by their choice) had an opportunity to be involved in "Guided Interactions" with their brother/sister with special needs, or another special needs child in the program. These guided interaction sessions were typically held once per week for 15-20 minutes at a time. A staff therapist organized and helped to structure these sessions. The child with special needs was assisted by the child's individual teacher-therapist (trainee). The rationale for these sessions was based on many of the siblings' histories of giving up feelings of self-satisfaction and pleasure in order to interact in ways that they felt were necessary to meet the needs of the child with special needs. In other words, these siblings consistently put their needs "on the back burner" while they attempted to meet the perceived needs of the special needs child.

Some siblings seem to miss out on experiences and pleasures of child development such as typical play, mutual sibling interactions, and so on. Although siblings seem to miss out on many of these experiences because of the necessity

created by their family situation in which they were often required to perform many household chores and responsibilities, what seemed to happen for some siblings was a strong feeling that their role in the family was just to do the said chores and responsibilities. For some siblings this feeling became so powerful and strong that they were not able to develop multiple roles in their existence. The purpose of these guided interaction sessions then was to offer the sibling and the special needs child more ways to interact that were both mutually satisfying and enjoyable. In other words, the main objective was for everyone to have fun and to enjoy each other's company versus participation in a teaching structure per se.

For the purpose of coherence, this curriculum is divided into sections as follows:

Weekly Themes -
Sample of Activities -
Pre and Post Program Questionnaires -

WEEKLY THEMES

Six weekly themes, developed largely from the issues and needs described by parents as well as siblings and by experience gained from prior groups, were addressed during the 1984 Summer Sibling Program. These themes were designed with the intent of helping siblings and staff members investigate individual and global issues and anxieties as well as some of the pleasures and strengths resulting from having a brother or a sister with a handicapping condition. As the program went on, the content of thematic areas moved from a broad group focus to more individual analysis. Activities for both sibling groups generally contained a combination of interactional, cognitive, emotional, and physical components. Free time and unstructured activities were interspersed with content activities.

The six weekly themes are briefly outlined in the following section. A more detailed description of specific activities will follow this section.

Week 1 - INTRODUCTION (Program and Social)
"Let's Get To Know Each Other"
The primary focus of the first week was to facilitate the bonding of the group. Activities were designed that were largely socially oriented so that sibling participants could get to know the other participants, get to know names and to build bonds which would hopefully help to bring about personal growth and development. In addition, a secondary focus of the group was to help familiarize the group with the programmatic rules and to give them a beginning sense of organization and format for the coming program.

Staff attempted to get input from siblings regarding their desires as to activities they would like to participate in, and also to get the sense of what sibling participants' expectations were. Sibling staff attempted as much as possible to help clarify expectations for sibling participants and for the sibling group. Also, a major focus of this week was to offer siblings a sense that this program was for them; that the siblings were here for their own needs rather than attending to help out their brother or sister with special needs. We began to give the siblings as much of a sense of separateness as possible. Consequently, activities were designed to focus on a sense of self and individuality. Some of these activities included games which entailed asking and/or remembering the names of other participants; sharing things such as likes or dislikes of each participant, an opportunity to ask other participants about some of their favorite things; self-collages; and free time designed to further instigate forming of friendships. On the last day of the group for that week, siblings were asked to bring in pictures of their family. The focus of that day was that every family was unique. Those siblings that brought pictures in and/or drew their own pictures, were able to label each family member and give a little bit of information about their family.

Week 2 - SELF-IDENTITY, SELF-ESTEEM
"Who Am I?" and "What Am I Here For?"
The primary goals of this week were to increase the siblings' awareness of themselves and their identity and to facilitate the growth and awarenes of self-esteem. A more intense focus was to allow the siblings to practice and to accept their role/identity as one of involvement with the special needs brother or sister but also separateness from them.

Initially, siblings' identity was sometimes intertwined with the identity of their brother or sister who had the handicap. This was visibly demonstrated during a group activity in which siblings made a collage telling a story about who they were and what they like. Siblings needed much more guidance and direction by group leaders than was anticipated. One reason seemed to be that the siblings had trouble thinking of things about themselves and what they enjoyed doing without associating it to their brother/sister and the role they took within their family.

For most of the siblings that participated, many presented throughout the entire week a need for continuous clarification of what they were in the sibling group for. In addition, it seemed necessary to split out what their special needs brothers/sisters were there for. A sibling staff leader promoted a discussion that surrounded the issue of why do the siblings think their brothers and sisters were at the special intervention program. Siblings offered a wide range of responses. Some of these responses included: "They needed help learning." "To learn how to talk." "My brother talks, but not in our language. He has his own language." "Sometimes he doesn't put words in the right order." "She repeats things." "If I say something that he doesn't know, he'll just sit there and say it back." "I suppose it's to help him understand what I mean." "Terry makes squealing noises." "Sometimes we play a game where I say 'Get in position,' and Terry repeats it over and over again — get in position, get in position."

For some siblings that were strong caretakers and had an extremely difficult time separating from their brother/sister, staff needed to offer them a considerable amount of emotional support and guidance in order to facilitate the separation process in a healthy way. Some siblings had a difficult time even remaining physically away from their brothers or sisters. For instance, one 9-year-old child, Steven, seemed to continuously wander away from the sibling room and was almost always found to be in the same classroom as his special needs 3-year-old sister. Teacher-therapists for the special needs child shared on many occasions that upon Steven's entering the classroom, he would immediately begin to take over caretaking responsibilities for the special needs child and would often show anger at intervention from the teacher-therapist and/or sibling staff.

With the focus on further development of a sense of self, activities were designed that attempted to focus on the sibling as an individual and to highlight multiple characteristics of the siblings' being. Several activities were done that began to explore siblings' feelings in certain situations in addition to further labelling and exploring certain sibling traits and characteristics such as favorite foods and other likes and dislikes. Other activities were designed such as the turf maps, that graphically depicted how the sibling perceived his or her immediate physical environment. Several long-term projects including the last day of school carnival

and a fundraising bake sale were started this week. The long-term aspect of several activities, (bake sale, carnival) offered several benefits to siblings. These activities allowed siblings to initiate and accomplish a positive action for their brother/sister with the handicapping condition. This was not a parent-initiated interaction, but totally the offering of siblings which helped to aid their feelings of individuality and self-worth.

The last day carnival was a major event for everybody in the program. Siblings worked hard and for a long time on several activity projects. Many fun activities (musical chairs, fishing pond, ring toss, pinatas) were designed and offered a structure for the special needs children to enjoy themselves within. Siblings gave prizes to all the children for their participation. The carnival was also something the siblings could do for the special needs child that simultaneously contributed to their own sense of self-confidence.

Week 3 - SIBLING RELATIONSHIPS WITH THEIR SPECIAL NEEDS BROTHER OR SISTER

"He May Be Different, But He's My Brother"

The goals of this week were to explore the sibling's relationship with their special needs brother or sister. If there were other children in the family, the sibling's relationship with the other siblings in the family was also explored. We also attempted to increase the sibling's awareness of some of the issues between siblings — with and without special needs.

Many of the activities that were done this particular week were based on creative dramatics. A lot of role playing and charade-type activities were done that attempted to offer the siblings a physical kind of medium in order to express their thoughts and feelings. For example, family charades were designed to allow the siblings to re-enact situations that had occurred between themselves and other family members. At the conclusion and/or during such activities, staff therapists would facilitate a discussion to help the sibling better express his/her feelings regarding the situation and to come up with coping alternatives.

Week 4 - UNDERSTANDING HANDICAPS

"Johnny Is Someone Too"

The goals of this week were to increase the siblings' awareness and understanding of a broad range of handicapping conditions. Siblings had an opportunity to be involved in further exploration and receive information on their brother or sister's particular handicapping condition. In a more formal way, the concept of alternative coping strategies was approached in order to offer the siblings at least some sense that there were alternatives to the ways that some of them were feeling and responding.

Activities for the week were based on a wide variety of handicapping conditions. Books and other literature were available for siblings to read and/or peruse.* For the young children, some stories were read to them that offered further information and insight into a wide range of handicapping conditions including deafness and blindness. In addition, siblings had an opportunity to experience "firsthand" what it was like to have a handicapping condition. Activities were done that also focussed on what it was like to be a special needs person, how to

compensate in the world, and some of the differences in relationships that developed because of the special needs that people possessed.

Staff could see many of the children "practicing" or trying to further experience the effects of a handicapping condition. Several parents also reported that their children were trying some things out at home. For example, one 4-year-old, Paula, became strongly interested in deafness after hearing the story, My Sister is Deaf, by Jeanne Whitehouse Peterson. After the story was read to her group and the children went on a bathroom break, I saw Paula running down the hall and asked her to slow down. Paula responded, "I can't hear you. I'm deaf!!"

Paula's mother called the next day and said they had had an interesting evening. Paula continued "practicing/pretending" to be deaf. In order to get her to respond as expected, family members needed to communicate with gestures!

During this week many of the confusions and misconceptions about handicapping conditions and about the specific handicapping condition affecting their brother or sister began to surface. It seemed as if some of the siblings almost understood a magical-type connection between the chronic condition and an (un)related entity. For instance, one 12-year-old sibling (who had participated in the sibling group in years before) had revealed that she thought that her multiply handicapped, psychotic sister had developed her difficulties because of a large number of mosquito bites that she had received when she was three years old! Another sibling wondered if when he turned five he would also become autistic.

*See bibliography for sample listing of books used.

Week 5 - FAMILY SYSTEMS

"It's Okay To Be Different"

All participants had an opportunity to discuss and personally examine real and perceived differences in their own family. Activities began to emphasize the family operating as a system and as one unit, or several units within a unit. Some attention was directed towards the siblings' role in this system. Discussions focussed on similarities and differences between families and characteristics of each individual family and its coping style. Siblings' personal degree of comfort and willingness to share family issues was highly respected as was confidentiality for information that was revealed. Some siblings at this time became more interested in meeting individually with a staff person to discuss individual issues further. Programmatic goals for the week were to facilitate the siblings' awareness of family systems in a very broad sense. Other more specific goals included: to increase the siblings' ability to recognize a variety of special needs within their family and to increase siblings' awareness of the impact of individuals with special needs upon other family members. Siblings were also encouraged to express the variety of ways that their brother or sister with special needs impacted upon the siblings' world outside of the families such as at school, playing with friends, at a shopping center, and so on. Siblings shared their experiences with a wide variety of behavioral difficulties: "If we're at the fair, she always tries to run away." "When Terry plays with somebody under her age, she pushes them and hurts the other kids." "Once in the grocery store, Kathy started jumping up and down on sacks of flour."

In order to offer siblings a sense of the concept of a family operating as a system, an activity was designed around the building of a family mobile. Siblings had an opportunity to choose from magazines or to draw representations of various family members. Siblings were given instructions to place family members near other family members that they were strongly connected to as they were designing their mobile. At the conclusion of the activity, siblings participated in a discussion in which they shared how each family member interacted with the other family members and how their family operated as a unit.

Other activities for the week included more role playing which involved re-enacting family situations that were difficult, confusing, or stressful — common occurrences for them. At other times, open-ended role playing was initiated in which siblings had an opportunity to "direct" other siblings to participate in their role play and function as their family members.

Several discussions centered around siblings' relationships with other children in the neighborhood or with their special friends. A considerable amount of the discussion tended to center around how they communicated to their friends the concept that their brother or sister has special needs or how they explain to their friends why their brother or sister did what they did in the house. Siblings offered a wide range of statements pertaining to "things they like to say to their friends about their special needs brother or sister." These statements included: "She's autistic." "He can't help that." "He has a learning disability." "She's always like that." "It's not his fault that he's like that." "Go home or quit it." "Shut up." "Leave her alone." "Go home if you're going to call him names." "Whatever you do to him, I will do back to you." "Don't." "Quit." "Sometimes he doesn't understand what you're saying to him." "That my brother or sister is special in some ways." "He can't talk very much." "She has self-stims." "She's fun to play with." "She has a lot of tantrums." "He may be different, but he is my brother." "Be kind." "Like him." "Please be his friend, too." Parental and marital relationship stress was seemingly perceived by some siblings as worries with which they also needed to be concerned. Some siblings openly discussed and often worried about issues they felt were adding hardship and stress to their parents' lives. Siblings expressed some concerns over parents' physical and emotional health ("My mother is getting so run down." "My dad is smoking a lot of cigarettes."), other financial difficulties, marital conflict, and their parents' conflicts over whether or not to have more children.

Some of the positive statements that were noted during discussions included
- I like having Sally more rowdy, because she likes running around. That's more fun.
- When I can't find anybody to play with, he's there.
- That he likes and plays with me.
- When we went camping, Dad took us to the store to get a little car to play with. Jason then wanted me to get one just like his.

In conclusion, it was hoped that through the expression of feelings, some of the feelings of isolation due to the perceived uniqueness of one's family would dissipate. This topic also sparked the beginning of peer brainstorming and idea-sharing about behavioral alternatives.

Week 6 - WRAPPING UP

"Saying Good-Bye"

The focus of this week was to look more specifically at other coping strategies, look at some issues towards the future, and to offer some sense of wrap-up/conclusion in preparation for the end of the program. Many discussions and activities centered around separation themes — separation from new friends, from the program, and from the daily support.

A wide variety of activities were designed for the week. Some of the activities tended to reiterate themes and confusions that were apparent as the program developed. Although the focus of these activities was on clarification, most of the activities tended to conclude in a discussion centering around what else could be done.

Existential and inexplicable issues of hope, fear of the future, and uncertainty regarding the development/aging process were often the topic of discussion. The group was able to offer siblings a setting in which to raise often ambiguous, unanswerable issues and questions, receive objective and realistic information about potential occurrences in the developmental course of their life situation.

Because siblings sponsored a carnival on the last day of school, a large portion of the week was spent finishing up activities and materials that were going to be used for the carnival.

SAMPLE OF ACTIVITIES

The following section offers a sample repertoire of activities that were used during the sibling program. The activities are divided very generally into areas based on their purpose, such as introduction, self-identity and self-esteem, and understanding handicaps.

Although the number of participants is often stated for a large group (of 20-25), most of the activities could be designed for smaller groups. The activities can also be modified for individual children to better meet their needs pertaining to their age, family situation, etc.

CLUE GAME

GOALS: To introduce group members and to help members learn the names of participants.
To familiarize group and staff with each other and learn special characteristics of group members.

HOW TO: Each person writes something about themselves on a piece of paper and puts it in a box (i.e. I like to swim. My favorite food is —.). Someone takes a slip out of the box, reads it aloud, and tries to figure out whose characteristic that is. When the correct person is identified, they tell about themselves and then pick a slip from the box.

TIME INVOLVED: 45 minutes

 # OF PARTICIPANTS: Any

BALL GAME

GOALS: To learn names and make introductions.
To familiarize staff and group.

HOW TO: Everyone is in a circle. The start of a sentence is stated (i.e. On a warm sunny day I...). A ball is tossed or rolled across the circle. The person receiving the ball states their name and finishes the sentence, then rolls the ball to someone new.

TIME INVOLVED: 20-30 minutes

 # OF PARTICIPANTS: Any

FROZEN BEAN BAG

GOALS: To facilitate interaction.
To work on group cooperation and helping skills.
To form a sense of group and to facilitate bonding.

HOW TO: Each child has a bean bag on their head and the leader (either another child or a teacher) instructs them to turn, run, jump, hold hands, etc. When a child's bean bag falls from his head, another child must come over and put it back on the head without losing his/her bean bag.

TIME INVOLVED: 15 minutes

 # OF PARTICIPANTS: Any

AGES 4-8

Introduction
Sibling relations
Understanding handicaps

TRUST WALK

GOALS: To gain a sense of what it would be like to have a condition which impairs or handicaps.
To learn to trust others in your group.

HOW TO: In pairs of two, have one child blindfolded and the other child take the first for a walk, taking him/her to different places and find different things (i.e. a drinking fountain, etc.). Then have the children switch roles. Discuss.

TIME INVOLVED: 30 minutes

 # OF PARTICIPANTS: Any

SAMPLE OUTCOME: One 4-year-old practiced a wide variety of handicapping conditions throughout the day at home and at school. She would pretend to be blind, be missing an arm, or deaf. In fact, this child's mother called the next day and conveyed that she went home and practiced having special needs at home. Apparently throughout dinner, her family needed to use "sign language" to her to communicate!

TURF MAPS

GOALS: To talk about and draw your area, your special places, etc.
To bring out feelings connected with different areas of the house or neighborhood.
To increase self-awareness.

HOW TO: Have children draw a map of their house and/or neighborhood. Have them mark things that stick out in their mind as being in that area. Discuss or draw what happens in each room and what the child feels is his/her territory.

TIME INVOLVED: 45-60 minutes

 # OF PARTICIPANTS: 20 (approximately); smaller groups for discussion.

SAMPLE OUTCOME: One 12-year-old boy drew a map of his house which was obviously not a scaled drawing. This child focussed in on his feelings of lack of individual space and intruded-upon personal boundaries. He drew a very tiny bedroom for himself, a small bedroom for his parents, and a very large bedroom for his brother, Jimmy. He drew great detail of Jimmy's room, especially focussing in on Jimmy's toys used for self-stimulation, which the sibling often described as extremely upsetting to watch or be around.

HOUSE-TREE-PERSON

GOALS: To seek information about the child by discussing the house, tree, and person in relation to themselves.
To facilitate increased self-awareness for the sibling.

HOW TO: Draw a house, a tree, and a person. Discuss each in relation to the child.

TIME INVOLVED: 30-60 minutes.

 # OF PARTICIPANTS: Any; smaller groups for discussion.

SAMPLE OUTCOME: One child drew a darkly colored weeping willow tree to represent herself. This child was being worked with individually by a staff therapist because of her depression. Following this activity, on a 1-1 basis, this child was able to talk about her feelings of sadness, lethargy, and anger.

AGES 4-12 Self-identity

BUTTERFLY PAINTING

GOALS: To stimulate imagination and creativity.
To increase self-awareness and insight into one's thoughts, fantasies, needs, etc.

HOW TO: Each child has a piece of paper, paints on it, (nothing structured, just drops or lines, etc.), then folds it in half. Then the child finds things in the paint (i.e. happy face, snake, etc.) and outlines them in marker. Have children share findings.

TIME INVOLVED: 20-30 minutes

 # OF PARTICIPANTS: 10-15

ANIMAL AS SELF (OR FAMILY)

GOALS: To better express self (or family).
To identify qualities in self (or family).

HOW TO: Have the children either draw or cut from magazines, an animal that they think represents themself (or each family member).
Share with the group.

TIME INVOLVED: 30-40 minutes

 # OF PARTICIPANTS: Any

SAMPLE OUTCOME: One child found pictures of soft, fuzzy animals to depict herself. She labelled herself as the one "everyone has to get love from." Another child drew a picture of a dragon to represent her sister with special needs.

AGES 4-12

Self-identity
Self-esteem

SELF COLLAGE

GOALS: To better express oneself.
To share self with others.
To get to know each other.
To help sibs separate themselves and their roles from others (especially in the family system).

HOW TO: Cut pictures from magazines, etc. that represent you and make a collage with them. Follow activity with a discussion.

TIME INVOLVED: 1 hour

 # OF PARTICIPANTS: 20-25 maximum for the activity.
Break into smaller groups (7-10) to share projects and discuss their meaning.

AGES 4-12 (split in two groups) Sibling family relations

ROLE PLAYING

GOALS: To experience other roles.
To express oneself.
To use one's imagination.
To gain a broad-based sense of differences, difficulties and strengths in all people (and families).

HOW TO: Have the children (one or two at a time) act out a person (mother, police, etc.) or have them act out a short scene (i.e. you are a patient in the hospital and you need to have an operation; you're scared and need to talk to someone, etc.).

TIME INVOLVED: 30 minutes

 # OF PARTICIPANTS: 10-15

FAMILY MOBILE

GOALS: To identify family members, how they relate and interact with each other.

HOW TO: Have children draw pictures or make name tags for each member of the family. Tie the tags from a hanger at any length and in any order. Discuss why the child put each one where they did and what happens when "the wind blows" (representing the interactions of the family as a unit).

TIME INVOLVED: 30-60 minutes

 # OF PARTICIPANTS: 10-15

AGES 4-12 Family relations

FAMILY COLLAGE

GOALS: To gain an increased awareness of self and familial characteristics. To develop an understanding of the broad-based differences in all families.

HOW TO: Cut from magazines or draw something that represents each member of the family. Discuss.

TIME INVOLVED: 30 minutes

 # OF PARTICIPANTS: Any

AGES 4-8
9-12

Family relations

FAMILY SCULPTURES

GOALS: To help develop further insight into one's family system.
To gain a deeper understanding that all families are unique (have strengths and weaknesses).

HOW TO: Have a child be "director" and choose someone to represent each member of their family and direct the "actors" as to what to do that their family does. Discuss as activity is being done and at conclusion of the activity.

TIME INVOLVED: 60-90 minutes

 # OF PARTICIPANTS: 10-15

DRAWING WITH HANDICAPS

GOALS: To further experience coping with a handicapping condition.
To gain an understanding of a wider scope of handicaps.

HOW TO: Have the children draw blindfolded, with no hands, using the "wrong hand," with mouth, feet, etc. Discuss.

TIME INVOLVED: 30-60 minutes

 # OF PARTICIPANTS: Any

BLIND BOX

GOALS: To gain a feeling of sensory loss.

HOW TO: Place items in a box, blindfold the child and ask him/her to find a specific item or have the child pick out an object and describe it to the rest of the group. Discuss as activity is being done.

TIME INVOLVED: 30 minutes

 # OF PARTICIPANTS: Any

TOURS OF SPECIAL NEEDS CLASSROOMS

GOALS: To better understand special needs children's classrooms.
To observe teachers and special needs children playing.
To better understand the similarities and differences in the special needs children attending the program.

HOW TO: Talk about the room you will be going into. Discuss some of the behavioral characteristics they will be observing. It is helpful to meet with the classroom teacher to find out what activities will be occurring, what the goals are, etc.

TIME INVOLVED: 15 minutes

 # OF PARTICIPANTS: 4-6 at a time.

AGES 4-8 Free play

FREE EXPRESSION CREATIVE DRAMA

GOALS: To calm and relax the children.
To facilitate cooperative play.

HOW TO: Group leader gives instructions as to how the children should tangle themselves together or if they should form something (chair, zoo, etc.) with their bodies, all working as a group.

TIME INVOLVED: Any (average 30 minutes)

 # OF PARTICIPANTS: 10-15

CONCLUSION

In his book, Family Therapy in Clinical Practice (1978), Murray Bowen postulated that children do not seem emotionally traumatized by the condition itself that is disturbing or handicapping. Similarly, our staff's impressions based on experiences with the sibling group suggest that it is more the anxiety, reactivity, and imbalanced equilibrium states that create emotional distress and personal crises. Clinically, some of our impressions were as follows:

- —The work with siblings seemed to have a "ripple effect" on the daily actions and interactions, self-esteem, and family attitudes. The skills which siblings gained seemed to have positive outcomes for their brother or sister with the handicapping condition.
- —Although siblings face many similar issues, they were at different levels of understanding and adjusting to the special needs child's condition. If siblings were better able to share and develop more insight about the impact of the handicap on their life, they began to spontaneously produce alternatives to action and expand problem-solving skills.
- —As the group process went on, there was a progression to greater peer-to-peer support and problem solving capability independent of the directed guidance from the sibling leaders.
- —The majority of siblings repeatedly expressed a strong desire/wish for their brother or sister to be and look "normal."
- —Female siblings talked more about caretaking and household responsibilities than male siblings. Females also appeared as the most "at risk" for overburdening themselves or by accepting developmentally higher than typical responsibility in these areas.
- —The oldest child in the family also seemed to hold more household and caretaking responsibilities. When the child with the handicapping condition was the oldest, the next oldest child took on the extra responsibilities.
- —Siblings we came in contact with were generally happy and emotionally healthy, but at times had the propensity to become overly stressed, distressed, or disturbed.
- —Siblings gradually began to integrate what was learned in the group and began to apply this knowledge in more typical living situations (from our observations and from parental reports). The concept of problem-solving began to occur more regularly. Siblings spontaneously began to figure out what could be done differently during times of distress, crisis, or when a problematic incident arose. Siblings seemed to feel better, less anxious, and responded more adaptively.
- —As siblings increased their understanding of the condition in ways that might affect families in general, they began to grow in understanding of how it affected their own family. Siblings developed new skills in behavior management, play, communication, and child care, often reinforcing what parents were attempting to do.

The "Guided Interactions" were one of the most difficult activities to schedule and to structure. Some siblings changed their feelings about participation on a fairly regular basis. It seemed that initially everyone wanted to spend time with their

special needs brother/sister. As the program went on, the staff therapist supervising the sessions would many times need to approach the sibling and ask if he/she desired a guided session on that particular day. We always respected the response from the siblings and usually tried to follow up a change in feelings with an individual session or meeting.

Usually the sibling was guided not to caretake or function as a co-therapist, parent, or behavior modifier. We discovered many times that the sibling's role in the family or self-image was that of a caretaker. Consequently, strong feelings of responsibility developed that often transpired into feelings of over-responsibility, guilt, anger, incompetency, depression, and so on. When a special needs child was not able or willing to "comply" or perform as expected, some siblings became extremely disappointed and/or saddened by such experiences.

A sampling of issues that arose during the guided interaction and during other group components included:

- —If the handicapped child made progressive developmental changes which required less assistance and caretaking from the sibling, what happed to the role of the sibling in the family? We often observed that some siblings would then "almost sabotage" the special needs child's development in order to further maintain his or her role. Some siblings appeared extremely fearful of losing their well-grounded role of caretaker within the family system.
- —Some siblings seemed to miss out on experiences and pleasures of child development.

Over time, most siblings seemed to gain new and different strategies for "being with" their brother/sister. They appeared to go through some changes in getting to the point of mutual enjoyment. At times we saw anger at the special needs child's teacher (maybe for interfering in the well-established caretaking relationship), sometimes anger at the special needs child for not responding or tuning in to the sibling, and sometimes there was noted an "apparent lack" of visible feeling or emotion toward the special needs child (i.e. "I don't care" and so on). As some of the siblings began to get a better sense of themselves and their needs separate from the special needs child, it seemed as if they could better relax and enjoy the interaction for what it was, in its purest form.

This curriculum has attempted to offer a theoretical and practical approach to address the perplexing and pervasive effects of a puncture to the family system by one member's handicapping condition. Just as parents try to understand the condition and how it affects them, siblings move toward adaptation sometimes successfully and other times maladaptively. This curriculum described one way of exploring how a handicapping condition in a child might affect that child's brothers or sisters. This curriculum also described one means of responding to the needs of such siblings within a support group.

Even though the results that we received from the pre-and post-program questionnaires were not of a formal and a standardized nature, these informal evaluations strongly suggested positive benefits to siblings attempting to cope with some of the stresses evolving from a family system imbalanced by the diagnosis of a child's handicapping condition. Parents and siblings both described

that siblings seemed less anxious and better able to realistically and adaptively live with the ongoing and painful stresses within their family. It is important to keep in mind that sibling functioning, similar to parental functioning, might disintegrate intermittently over time, with or without intervention. It might be that with continued support and guidance such as by the model described within this curriculum, siblings' ability to cope realistically and adaptively in such a way that such periods of disintegration might occur less often and with less duration and require less therapeutic intervention in order to regain optimal functioning.

Siblings of children with special needs are indeed a unique population. They oftentimes are living in exceedingly stressed family environments and confronting frequently devastating life situations that are generally little understood by their schools and by their peers. In many ways they are living with invisible stresses that they can't share with the outside world. It is our experience that siblings need and can benefit from support. It is our hope that the availability of interventions such as the program outlined in this curriculum can play a small part in enabling the siblings' becoming better able to cope with stresses, develop meaningful relationships, express feelings, and fully experience the pleasure and the pain in their individual lives.

SECTION III

PRE-PROGRAM QUESTIONNAIRES

In the spring of 1984, one questionnaire was mailed to parents and one to siblings that was designed to provide staff with (1) a description of the siblings' understanding/perceptions of the child with special needs, (2) interactions with the special needs child, (3) issues they would like to have discussed, and (4) desired goals/outcomes of the group.

Parent Pre-Program Survey

In order to gain a sense of how parents understood the relationship between the child with special needs and siblings, parents were asked to describe their interactions. Most of the parents referred to feelings of ambivalence and fluctuating interactions between the children. It seemed that there were times that these children were better able to play together and interact than other times. Parents offered dichotomous descriptions of the siblings' interactions including a focus on positive interactions ("He does a good job of getting her involved in play at home") and at the same time some conflicted and stressing interactions ("He 'bugs' the special needs child").

Some parents indicated that siblings felt a wide range of emotions while interacting with their special needs brother or sister. Some parents made reference to the fact that siblings became frustrated, had resentment, felt the special needs child got pampered a lot, and siblings found it hard to relate to the special needs child. At the same time, some parents expressed more positive feelings on the sibling's part including being "best friends" with the special needs child, having a lot of patience, being very close and showing affection and readily sharing.

The majority of parents expressed concern for the adjustment of the siblings to the child with special needs. However, a large number of parents also did indicate the siblings tended to adjust positively to the impact on their family. Parents alluded to the siblings' feelings of frustration, confusion, tolerance, difficulty expressing feelings, trying extra hard to help, and holding anger inside.

Staff members of the Sumer Sibling Group wanted to design activities for the siblings in order to help address the issues which parents felt important and needing to be discussed within the group. A large number of parents felt that issues surrounding coping and education should be looked at. These parents indicated a need for siblings to gain a greater understanding of the condition and its impact. In addition, parents expressed a desire for siblings to gain behavior management, teaching, and interactional ideas. A second major focus suggested by parents was to hopefully develop a focus on the siblings' self-esteem and venting of feelings. Many parents expressed that they wanted siblings to feel that

they had a place where they could share their feelings and worries and not only gain staff, but also peer support. A third focus desired by parents was to offer the siblings some sense of their parents' coping and adaptation. For instance, a reference was made to help siblings understand some of the more specific demands placed on parents, why parents need to use different discipline and behavior management strategies, and for siblings to gain an understanding as to how difficult the child can also be for the parents. Related to these concerns, parents largely recommended that goals and outcomes of the group be to offer siblings a better understanding of the handicapping condition as well as additional strategies for interacting with and coping with the handicapped child. It was felt that siblings needed to make supportive friends, gain more insight about their own feelings, and learn to feel better, especially reducing feelings of frustration and of extra responsibility.

Sibling Pre-Program Survey

Siblings were asked to describe their brother or sister with special needs. Almost all of the siblings described one behavior or one area of difficulty as their way of understanding the condition that handicapped their brother or sister. Some of these areas included such things as, "She has to learn to cope," "He needs to learn new things," "My brother is different and kind of strange," "He seems to need help," "He needs help in communication," "He can't go outside by himself," "He can't/doesn't talk," "They get spacey and flap their hands and don't listen." All of these siblings acknowledged that the needs of their brother or sister did affect them. Some of the siblings suggested feelings of self-responsibility ("I need to help her learn to talk, I have to watch her more often than other kids do, I have to be more patient, I have to watch her a lot"). Other siblings indicated feelings of sadness and feelings of frustration and anger. At the same time, most of the siblings were able to indicate something that they liked to do with their brother or sister. Most of the things they listed included a motor-based, primarily non-verbal activity such as playing kickball, break dancing, playing basketball, or wrestling.

The activities that siblings felt were the hardest to do were those that involved and required greater understanding and communication skills from the special needs child. Siblings described considerable difficulty in talking to or attempting to get the special needs child to talk. In addition, they expressed frustration and difficulties at getting the attention of the special needs child, trying to get the special needs child to listen, to share, or to learn a new skill or activity.

THE TAYLOR QUESTIONNAIRE

Mid-way through the six-week summer program, 17 siblings completed a modified version of the Taylor Questionnaire, a series of 46 "yes-no" questions which provoked more specific information from siblings regarding their wishes, thoughts, and feelings about their brother or sister. All of the sibs did not complete the questionnaire because of their difficulties understanding the questions (due to their developmental age), absences, or choice of the sibs not to. Siblings responded to such matters as:

—I wonder what kinds of things my brother or sister will be able to do when he/she grows up.

—I wish I could be extra smart for my parents' sake because my brother/sister is not.

—Sometimes I wonder if my parents love my brother/sister more than me.

Some of the themes that became apparent as a result of the questionnaire were that of:

—caring.

94% stated that they liked having their brother/sister in the family;

82% stated they liked to take their brother/sister with them to go places;

—feelings of over-achievement, over-accomplishment.

76% wished to be extra smart for their parents' sake because their brother/sister is not;

53% tried to do well in school to make up to parents for their brother/sister being retarded/autistic;

—concern regarding family life.

65% stated life in their family is quite a bit different from life in the families of friends because of their brother/sister;

47% stated at times they do not like the way their brother/sister interferes with the family's plans;

47% stated that parents feel badly because they cannot do more to help my brother/sister;

—inter-personal issues.

58% do not let people make fun of their brother/sister around them;
wonder how smart they were themselves;
there are times they do not like to talk about their brother/sister as being retarded/autistic;

—53% wonder what kinds of things their brother/sister will be able to do when he/she grows up;
wish they could talk to somebody about their problems and worries about their brother/sister;
at times do not like the way their brother/sister interferes with their plans;
worry about whether they're as good to their brother/sister as they should be;

47% think parents feel badly because they cannot do more to help their brother/sister;
do not have trouble explaining to friends about their brother/sister;

—concern for the future.

53% wonder what kinds of things their brother/sister will be able to do when he/she grows up;

47% do not think their brother/sister will ever live in an institution;
wonder if their brother/sister will be able to have a job;
do not wonder if their brother/sister will always be retarded;
do not wonder if their brother/sister will be more trouble when he/she gets older;

One of the interesting results derived from the Taylor Questionnaire was the contradictory kinds of responses that the sibling participants offered. For instance, siblings seemed to present conflicting statements regarding their feelings over not wishing to be extra smart for their parents, their ease/difficulty in sharing information with their friends about their special needs brother or sister, wondering about their brother or sister's future (job, living situation) yet not wondering if they were or were not going to always be retarded. At the same time, siblings seemed to express somewhat conflicting views as to the impact that the special needs child had on their life such as the ease or difficulty in which they were able to do things with or without their brother or sister. Sibling staff interpreted these contradictory statements as stemming from siblings' ambivalent feelings towards their brother or sister and towards their at times very difficult living situation.

POST-PROGRAM QUESTIONNAIRES

Sibling Post-Program Questionnaire
In order for sibling staff to get the most comparative type of information/data for review of the sibling program, parents and siblings were asked to complete post-program questionnaires. Siblings were again asked to give a description of their brother or sister with special needs. By and large, siblings were able to give more specific labels or descriptors for their brother or sister's difficulties. In addition, many of the siblings also gave more than a single-faceted description of their brother or sister's special needs, whereas on the pre-program survey siblings tended to focus in on one general difficult to manage behavior. Siblings were able to describe difficulties with expressive and receptive language, high tolerance for pain, difficulty playing with other children, tantrums and self-stimulation. Siblings indicated that their brother or sister's special needs affected them in such ways as feeling hurt, sad, wishing the child didn't have learning problems, needing to be more patient, needing to help the child a lot, and missing not being able to talk with him.

The majority of siblings completing the forms indicated that they enjoyed coming to the sibling group at least most of the time, learned some new things, and at least some of their time enjoyed being combined with the sibling group of the different chronological age.

Siblings claimed that they learned and benefited from the peer support. Most of the siblings indicated a positive impact from sharing about their brother or sister with special needs, and also from the support they received from others in the group who also had a brother or sister with a similar condition. Siblings tended to mention the skills they had gained (regarding behavior management, play, and interaction) with their special needs brother or sister.

Parent Post-Program Questionnaire
Parents conveyed that siblings tended to enjoy themselves at the sibling group. They specifically labelled that siblings enjoyed the types of activities that were done and enjoyed meeting and interacting with the other children. Siblings were felt to have become more aware of special needs and handicapping conditions, more aware of their own feelings, and were seen as better able to talk and share their feelings and perceptions about having a brother or sister with special needs. Other parents stated changes in their children such as seeing an increase in self-confidence, less continuous concern with the parental love and attention toward the special needs child, more understanding, patience, and tolerance of the special needs child, more ability to communicate with parents, and an increase in strategies for being with the special needs child. Parents also felt that siblings' lives outside of the family system were positively affected by their participation in the sibling program. Many of the parents went on to describe that siblings seemed better able to share with their friends in more accurate kinds of ways their brother or sister's special needs. Parents often heard siblings using more accurate labels to offer clarification as to their brother's or sister's difficulties.

APPENDICES

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PRE-PROGRAM SIBLING FORM

To be completed by Siblings 9-16 years old.

May, 1984

SIBLING SUPPORT GROUP

We will be setting up another group this summer, especially for brothers and sisters of special needs children. Our summer program will be six weeks long.

Minneapolis Children's Medical Center

We would like you to answer these questions as honestly as possible. We would also like to meet with you once before the summer program begins.

We hope that you join our summer group!

Your name _____

Your brother/sister attending the program _____

Your other brothers' and sisters' names _____

_____

1. Describe your brother or sister's special needs.

2. How do these needs affect you?

3. What kinds of things do you like to do with your brother/sister?

Minneapolis Children's Medical Center

4. What are the hardest things to do with your brother/sister?

We will be having a lot of different activities for you to do this summer. Please check those that you'd like to participate in:

_____ playing with your brother or sister in the program

_____ playing with other children in the program

_____ group discussion

_____ talent show

_____ work on a newspaper/book

_____ read a book about a "special" needs child

_____ over-night camping trip

_____ draw up an "informational" brochure

_____ write a book on autism for other groups of brothers and sisters

Write down any other ideas that you have for activities.

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Thanks! We're looking forward to a fun summer!!

May, 1984

PRE-PROGRAM PARENT FORM

Program for Autistic and Other Exceptional Children

SIBLING SUPPORT GROUP

Name of sibling _____ Birthdate _____

Parents _____

Address _____

Phone _____

Other siblings and ages _____

_____

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1. Did your child participate in the group last year? YES NO

2. Give a description of the special needs child who is attending the Program for Autistic and Other Exceptional Children (including interaction, communication, behavior and learning difficulties).

3. Describe each sibling's interaction with the handicapped brother or sister.

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4. Describe each sibling's adjustment to the handicapped brother or sister.

5. What issues do you see as important and needing to be discussed within the group?

6. What would you like to see as outcomes or goals of the group?

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Feel free to share with us any thoughts, feelings and information which you believe might facilitate your child's participation in the group and may assist us in designing the group.

Thank you for your time and willingness to help us set up a successful sibling group for the summer!

Program for Autistic and Other Exceptional Children

July, 1984

Post-Program Questionnaire - Sibling Support Group

Name of Sibling _____ Age _____

Name of Parents _____

Address _____

Phone _____

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1. Give a description of your brother or sister's special needs:

_____

_____

_____

2. How do these needs affect you?

_____

_____

_____

3. I enjoyed coming to the sibling group:

____ not at all ____ sometimes ____ most of the time ____ all the time

4. Please mark which activities you enjoyed during the summer:

____ Art with Kay

____ Working on carnival

____ Preparing for bake sale

____ Music

____ Video taped activities

____ Outside/gym

____ Making family mobiles

____ Clay-family sculptures

____ Creative drama/charades

____ Writing activities (such as Pass on Poetry)

____ Experiencing handicaps

____ Playing with your special needs brother/sister

____ Story time

____ Newsletter

5. Did you feel you learned some new things this summer?

____ I didn't learn anything new

____ I learned a few things

____ I learned a lot

6. What was the most important thing you learned?

_____

_____

7. I was usually able to get help or talk to a staff person when I needed to:

____ never ____ sometimes ____ almost always

8. How could the group be changed to make it a better learning experience for you?

____ smaller size of group

____ more staff people

____ larger or more classroom space

____ different activities

Anything else? _____

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9. Was your participation in the sibling program what you expected?

____ yes ____ no

How so? _____

_____

10. What was the most frustrating experience for you this summer?

_____

_____

11. What did you enjoy the most this summer?

_____

_____

12. We often did activities with the younger and older kids together. How did you like this?

____ I didn't like doing things with the whole group.

____ Sometimes I liked it and sometimes I didn't.

____ I liked to do things with the whole group.

13. Some people spent time playing with their special needs brother or sister during "guided interaction" sessions. How did you feel about these sessions?

____ The time was too much.

____ The time was too little.

____ The time was just right.

____ I didn't participate, but I wish I would have.

____ These sessions were/were not useful to me.

14. Are you interested in joining another sibling group?

____ during the school year

____ next summer

Thank you for taking the time to fill out this form. We hope to see you soon!

Minneapolis
Children's
Medical Center

August 3, 1984

Dear Parents:

We are attempting to put together information on our summer sibling program in order to help us design and implement future programs. We would appreciate it if you would answer the following questions, and return the form to us as soon as possible.

1. Did your child seem to enjoy coming to the sibling program?

   _____ yes _____ no

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2. What kinds of things did your child share with you about his/her experiences in the group? (i.e. activities, feelings, frustrations, their friends, etc.)

   _____

   _____

   _____

   _____

   _____

3. Please check if you saw any changes in your child over the six-week program.

   _____ in your child's affect, emotion

   _____ in your child's play with the special needs child

   _____ in your child's awareness or understanding of handicapping conditions

   _____ in the amount or kinds of information they shared with you

   _____ any other changes _____

Please describe these changes in more detail:

_____

_____

_____

_____

_____

4. One goal of the weekly sibling newsletter was to provide parents with a very general idea about some of the activities siblings participated in.

   Would you have liked more information about:

   _____ sibling activities

   _____ your child's participation in the activities

   _____ very general stages or changes siblings go through in adjusting to family stresses, such as the impact of a handicapping condition

   How do you feel this information could best be shared with you?

   _____

   _____

5. We are tentatively thinking of running a sibling group during the regular school year. At this point, our thoughts are to run the group for approximately a four-series session, sometime this fall. Are you interested in having your child participate in a sibling group during the regular school year?

   _____ yes _____ no

   If so, would you be willing/able to provide transportation?

   _____ yes _____ no

   Provide funding? (approximately $10.00 per session/out of pocket payment, insurance or medical assistance)

   _____ yes _____ no

   Please check the best time for the program to be scheduled:

   _____ after school (4:30-6:00 pm) _____ evening (6:00-7:30 pm)

   _____ same time as parent group (7:00-9:00 pm)

   _____ Saturday mornings (10:00-12:00 noon)

6. Please feel free to offer us any other input regarding the sibling program:

   _____

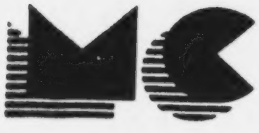
   _____

Thank you very much for taking the time to complete this form. If you have any questions, please call at 874-6139.

Sincerely,

Cindy Dolby Nollette
Program Coordinator

Minneapolis
Children's
Medical Center



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